CHAPTER 4: RESPONDING TO THE NEEDS OF PEOPLE WITH DISABILITIES

Whether considering the needs of a single person or building a system to meet the needs of many people, the fundamental interest is in *how* we support people with disabilities so that they may best achieve real life outcomes-lives that are not fundamentally different from what we ourselves cherish as full citizens. The focus moves away from facility-based care to communities where real people live real lives. The task becomes one of developing community capacity to genuinely welcome citizens with disabilities.

> ***"It seems to me a major roadblock in providing a consistent home/ community based system of care for children and/or their families is transportation (more specifically, the lack thereof)."***
> ***State Plan feedback***

Community Capacity

The concept of *welcoming* refers to the community's ability to respect and value people with disabilities. This includes the availability of ordinary resources such as housing, transportation, employment and education as well as opportunities for developing friendships and social interactions, advancing spiritual desires and exercising civic interests. Additionally, the concept of community capacity involves recognizing individual and unique desires and needs of people with disabilities and developing the additional specialty responses of care, treatment, service, accommodation and support needed for successful living in a community environment. Specialty responses include methods that respond to routine desires and needs as well as acute or crisis situations. They are often referred to as *models of practice.*

Over recent decades, but particularly in the last ten years, there have been advances defined as *best practices* or *emerging best practices*. These are models of practice that have demonstrated the ability, when applied correctly, to promote real and valued outcomes for people with disabilities. These outcomes relate to issues such as improved general health, protection and prevention of adverse events like homelessness or jail imprisonment, increased employment, opportunities to develop satisfying relationships and greater personal satisfaction. Additionally, advances in medicine allow people with treatable conditions such as mental illness or addictive disorders far greater freedom from troubling symptoms that interfere with meaningful community life. Taken together, community (natural) and specialty developments merge as the full array of accommodation, care, treatment, service and support that constitutes community capacity.

The *best* and *emerging best* practice models adopted in the State Plan are based on philosophical and theoretical frameworks that have varying usefulness among all disability groups. Some may be

implemented immediately while others will need to occur gradually. These are briefly defined below.

Consumer driven

This concept is often referred to as *consumerism* or *consumer empowerment*. The intention is to promote systems of support and/or services that are controlled by people with disabilities. Some models of practice may involve shared control, such as that in a psychosocial clubhouse, while others, such as drop-in centers or consumer cooperatives, are controlled solely by people with disabilities. Some models like Alcoholics Anonymous, Schizophrenics Anonymous and peer relationship and support building are defined solely as support oriented.

Opportunities for people with disabilities to take active participatory or leadership roles in public and private systems is a hallmark of consumer driven systems. This includes assuring that individuals are supported and accommodated, provided skill and knowledge acquisition opportunities related to their roles and responsibilities and compensated and/or recognized for their efforts.

Consumer friendly

Customer friendly systems pay attention to issues that affect actual consumer experiences with systems of service. These issues include concerns with ease of access, staff attitudes, accommodations made for physical and other disabilities and communication throughout all aspects of all systems—from the point of entry to the point of exit. This practice requires that management and provider systems alike operate in a manner that promotes a user friendly, responsive customer service orientation in all aspects of support, services, care and treatment.

"By our silence, we let others define us."
Susan Rook, recovering alcoholic & addict advocate

Self-determination

Self-determination incorporates a set of concepts and values underscorinf a belief that people who require support as a result of a disability should be able to define what they need in terms of the life they seek, have access to meaningful choices and have control over their lives. Within the state's public mh/dd/sa system, self-determination involves assuring that services and supports for people are not only person-centered, but person-defined and person-controlled. Self-determination is based in five principles:

- **Freedom** to live a meaningful life in the community.
- **Authority** over how a limited amount of dollars are spent for needed for service/supports.
- **Supports** to organize and obtain resources in ways that are life enhancing and meaningful**.**
- **Responsibility** for the wise use of public dollars.
- **Confirmation** of the important leadership that self advocates must hold in a newly designed system.

To move toward a life that is self-determined, families and individuals with disabilities need information, assistance and education to assist them in becoming skilled at making informed choices and in recognizing and choosing the services and supports they need. The system must be prepared to provide competent assistance when there is a need for specialized services, supports and treatments. Self-determination principles do not minimize or make marginal the clinical or treatment needs of individuals with disabilities. There is an expectation that people will be supported in and will be responsible for seeking out needed services in order to benefit from a life a full community citizenship.

Person-centered planning

Person-centered planning (PCP) is an on-going process fundamental to consumer driven systems, in which the individual with the disability assumes an informed and in-command role for life planning. For a minor child, the concept extends to the family group. For *any* person, the process includes other people who the individual invites to participate. Planning is focused on development of real life outcomes and a corresponding plan for achieving those outcomes. The process includes ensuring that individuals are fully informed and afforded opportunities to be supported in exploring new life experiences. PCP also includes developing responses for health and safety concerns, acute or chronic treatment needs, crisis contingency planning, services or programs that may be useful and desirable and any special supports that may be needed to increase opportunities for success.

"Consumers & families who participate in quality management & service monitoring activities should have avenues to report their findings to someone at the state level as well as to the LMEs."
State Plan feedback

Person-centered planning **is not** c*arte blanche;* that is, the process does not give full authority to do anything desired. Neither does it dump responsibilities on natural supporters or systems. *All* people express desires and dreams and work to pursue these life aspirations through the expansion of resources (particularly personal and natural) but also within the constraints of available resources. The PCP process acknowledges that services, treatment and care needs operate within practice standards and are not unlike what occurs in natural systems. The process accepts use of publicly sponsored specialty resources as the *financing of last resort* relative to an individual's plan.

Person-centered planning results in an Individual Support Plan (ISP). An ISP translates the learning acquired from the PCP into a set of real life outcomes and a corresponding set of methods, responsibilities and resources necessary to pursue and ultimately achieve those outcomes. Support plans also address crisis contingencies and health and safety issues. Specialty supports and services, including care and treatment that may be needed, are part of the ISP whether used occasionally or on a frequent, ongoing basis.

Cultural competence

Culturally competent systems acknowledge and respect the scope and breadth of diversity that characterizes contemporary society. People who identify themselves with a particular ethnic, cultural or religious grouping have established cultural norms or practices such as customs, language, symbolism, rituals and social or behavioral expectations. Cultural competence means that these cultural norms are recognized, accommodated and respected. Culturally competent systems, both management and provider, acknowledge and demonstrate appreciation and respect for human diversity.

Recovery

Recovery is a philosophical framework that recognizes and accepts chronic disability as part of the person's life-long experience. The concept of recovery has been traditionally associated with the alcohol and substance abuse recovery movement emphasizing self-help, mutual support and fellowship. Over the past several decades, recovery has emerged as a foundation on which best practice interventions for adults with serious mental illness are designed. For mental illness, the recovery approach can be compared somewhat to a person who undergoes a serious accident or illness and recovers from the acute event but retains some lingering residual effects or functional problems. A recovery-oriented model presumes that individuals can learn to effectively manage their symptoms, maximize their level of functioning and go on to attain a life of meaning, productivity and satisfaction. For both mental health and substance abuse, the recovery philosophy emphasis is on development of the individual's coping mechanisms and self-esteem primarily derived from learning, self help, peer support and pursuit of valued life roles.

"Eighty-seven percent of people in the recovery community say it is very important for the American public to know the basic facts about addiction and recovery."
The Alliance Project, 2000

Systems of support

This is a concept most often referred to as s*ystem of care* in connection with supports and services for children and families. Although NC currently employs this practice for children, the concepts are generic throughout all ages and disabilities. System of care is intended to promote stability and healthy development of life domains within the context of a natural community environment. The individual and people representing key close relationships are at the inner core of the system of support. Peers and professionals build from that core. As applicable, systems of support extend outwards beyond the specialty system to include other public agents and community resources such as schools, public health, social services systems, faith-based organizations and advocates.

Array of Services for Target Populations

Service and support selections for an individual's support plan (ISP) may be drawn from any or all of an array of options using the models of practice adopted by the State Plan and developed by the local service systems. Some specialty resources may be shared within various geographic areas or developed in cooperation with other agencies, qualified providers or public services. A key element for approval of each local business plan will be the creativity, innovation, breadth and inclusiveness of its proposed service array for targeted populations, including those with co-occurring disorders and other special needs, including diversity.

As local communities plan their capacity development strategies, it is important to distinguish the differences between and among the terms that, collectively, describe the public specialty system.

> *We want a more efficient use of services and better-managed resources. We should look at outcome-based services.*
> *State Plan feedback*

Supports are non-fixed, fluid, individualized arrangements intended to promote a natural community life for people with disabilities. These may be human, technical and/or financial resources applied to help individuals acquire natural housing, supported living, employment (supported and competitive employment), education (supported education) and other assistance needed by the person to operate in the community.

Services are defined as programs that serve as natural community substitutes, such as residential programs or day programs, that are typically in fixed locations (physical plants) and not individualized but rather structured to respond to a group of people.

Treatment (and care) is defined as single or multiple integrated interventions provided within a scope of practice such as psychiatry, nursing, social work, occupational therapy and many others intended to respond to behavioral, health, psychiatric, habilitative and/or rehabilitative needs of an individual. Treatment may also be provided as part of a service array in a fixed program such as community psychiatric inpatient or detoxification programs.

People with disabilities also need advocacy and personal assistance to help them take full advantage of available resources or ones that can be constructed in response to identified desires and needs. This kind of advocacy goes by many terms often used interchangeably, such as care management, case management, service coordination and others. For purposes of consistency, the State Plan adopts these definitions:

- *Case Management* is an overarching function involving five dynamic and interrelated processes: assessment, planning, linking, coordinating and monitoring for individual consumers. There are several case management models of practice that reflect variation in the manner in which the five processes are carried out and in the corresponding required set of skills.

- *Support Coordination* is a part of the case management function that involves facilitating person-centered planning in the event that an independent person, including a member of the individual's planning circle, or the individual is not facilitating the plan. Support coordination also refers to implementing and managing the ISP.

- *Assertive Community Treatment (ACT) and Home-based wrap-around (HB)* are sometimes referred to as *comprehensive case management* models. North Carolina defines these as *services* rather then *functions*. ACT is a self-contained community-based comprehensive service team, and HB *wrap-around* involves individuals who are able to perform the function of case management and also community-based therapeutic services. Both of these services include the functions of support coordination and clinical case management.

- *Care management* is an activity intended to assure that levels of care match the identified needs of the person-centered planning and assessment process and are cost effective. Care management is not an advocacy or personal assistance function.

- *Service coordination*, as used in the reform statute and the original version of the State Plan, is an administrative function designed to assure that all components of the local system operate in an integrated, consistent manner that is customer friendly. Service coordination is not an advocacy or personal assistance function.

The resources contained in an ISP are drawn from any or all of the array of services, supports, care and treatment as well as those that are individually crafted and completely unique to meet the special needs of the individual. The ISP should typically address the following areas.

Housing/residential

Housing/residential services are ideally obtained in natural community housing initiatives designed to ensure that an individual lives with maximum independence in the least restrictive settings, such as independent single or shared living quarters in communities with or without on-site support. Other options include:

- Living with family or friends with adequate support/respite services.

- Small, home-like facilities in local communities close to families and friends, with the goal of moving to a less structured living arrangement when appropriate.

Residential placements also include any equipment and supplies needed to assist in successful, long-term housing stability. Admissions to state or private hospitals, mental retardation centers, state schools or any other institutional facility are not permanent or long-term residential options

and are meant to be placements of last resort. Admissions to facilities are considered negative events and poor outcomes. As such, facility admissions can be viewed largely as failures of the system to recognize and act to meet the changing needs of an individual's condition or circumstances.

Transportation

A voucher system will be created to help individuals reach services. Vouchers can be used for public transportation or to pay neighbors to provide transportation. In areas where no public transportation exists, LMEs will design ways to assure access, including taking services or programs to people with disabilities in their communities on a regular basis. The LME may need to collaborate with local public or private agencies to pool resources and community facilities

"...it would seem that transportation is the key to getting people to where they can access services."
State Plan feedback

Treatment, symptom management, therapies

People who have psychiatric symptoms, substance abuse problems, developmental disabilities, co-occurring disorders, or other conditions amenable to medication management; physical, speech, or occupational therapy; or brief and intensive psychotherapy must have these services locally available. In urban areas, services can be offered in a broad variety of settings suitable to the needs of the individual. In rural areas, services may need to be taken to the area on a regular basis. Other interventions may include detoxification services, outpatient or inpatient substance abuse treatments with varying levels of intensity, therapeutic communities and services to people with co-occurring disorders.

Work, school, activity, leisure

There are many services teaching living skills that make the most of the individual's ability to adapt to his/her environment, engage in meaningful work, and develop satisfying, lasting relationships. These include rehabilitation; before and after school activities; pre-vocational and vocational training; employment, health and wellness education; substance abuse prevention or treatment; employment transition services and others.

All such activities need to emphasize personal empowerment and offer constant opportunities to learn, develop and exercise increasing levels of self-determination, recovery and control. Program activities need to flow with the natural rhythms of daily life (i.e. work/study in the daytime, recreation and play after work and on weekends). Programs may not be composed of static, repetitive activities that do not teach, develop, empower or guide the individual toward a more effective and independent lifestyle.

Wrap-around services

Wrap-around services can include virtually any support or resource dictated by the unique needs of individuals and their families. Examples include family respite supports, family education and training, various peer supports and activities, personal support, live-in caregiver, day supports, Assertive Community Treatment teams, case management and support coordination. Also included are assertive outreach, interpreter services, case consultation and any other services/supports needed to enable individuals to live successfully in their communities.

Crisis, emergency, including core emergency services

These include a range of emergency management services including short term diversion beds, crisis stabilization, after hours services, detoxification, facility-based crisis services, crisis hotline, walk-in services and inpatient hospitalization. The emphasis in emergency services must be on planning (including advanced directives in the ISP), early intervention and stabilization, or other strategies for avoiding the need for intensive inpatient or acute residential services.

In addition to the more traditional set of crisis/emergency services, the range of these services will also include community disaster response and recovery. Disaster response and recovery activities include crisis counseling, debriefing and defusing and grief counseling. Within available resources such activities must be provided to anyone who is affected by a disaster.

Special considerations

Planning and services that address the needs of women

While men and women with disabilities share many common experiences related to their conditions, systems need to recognize the fundamental differences as well. These differences are reflected in patterns of service utilization and in the life experiences of the individual. To meaningfully acknowledge these differences will require a shift away from gender-neutral service and system planning and a focus on unique needs. Systems better serve women when:

- Services are planned and evaluated with the involvement of women consumers and allied women's agencies.
- Services are provided with a holistic family-centered approach that includes services provided to children.
- Services and planning recognize consumer diversity in terms of ethno-cultural ancestry, heritage, age and sexual orientation.
- Impact of trauma/violence is acknowledged and addressed.
- Services sensitively and respectfully address issues related to sexuality, pregnancy and parenting.
- The benefits of woman-centered services are recognized, including housing and therapeutic settings in which a woman's privacy, security and social support needs are considered.

- The distinctive ways in which women experience dual conditions of mental illness, developmental disabilities and/or substance abuse are understood.
- Appropriate primary medical care is accessible for all aspects of physical health.

A new look at an old standby: prevention

There is a growing body of new knowledge about effective prevention. Much of the work on prevention effectiveness comes out of extensive research on alcohol and substance abuse, but the efforts have usefulness among all disabilities. Prevention programs are reaching a new level of sophistication that includes evidence-based practices, outcome evaluations and cost/benefit considerations. In recent years, developing and delivering prevention services and programs has become a specialty in its own right. In the field of substance abuse, the prevention specialist develops a continuum of high quality prevention services consisting of:

- **Universal prevention** – targeted to populations not identified on the basis of individual risk, such as a school curriculum and healthy living skills. (See core functions)

- **Selected prevention** – targeted to high-risk groups such as children of substance abusers.

- **Indicated prevention** – targeted to individuals with minimal but detectable signs foreshadowing substance abuse problems.

As an agency that purchases health care, the Division has an opportunity to effect change in the health status of the state by broadening the delivery system and incorporating prevention efforts alongside treatment, services and supports. Preventive interventions in physical health have been based on scientific evidence, and much has been learned about immunizations, smoking prevention and cessation, routinely covered preventive health screenings, and most recently, seat belt and helmet laws. Now there is evidence that risks also can be reduced for mental health problems, drug and alcohol abuse and physical illnesses in which onset is primarily related to behavior. By reducing risk factors and enhancing protective factors, many illnesses can be prevented or at least delayed.

As people become more informed about the effectiveness of risk reduction strategies for prevention of many mental health, developmental disability and substance abuse problems, they are more likely to demand these services. For example, individuals in recovery from alcoholism and drug addiction or those with some types of depressive disorders, may want preventive services for their children who are at high risk for similar disorders. Engaging individuals by offering a menu of activities known to promote health and wellness can increase their knowledge and involvement in making decisions to seek out and apply prescribed interventions.

The science regarding risk and protection is large, changes rapidly and varies across disabilities. Prevention programs need to build their activities on a base of evidence sufficient to justify mounting preventive interventions.

Examples from CSAT and the national Mental Health Association of the best prospects for obtaining measurable outcomes are:

- *"Prevention of initial onset of unipolar depression across the life span.*
- *Prevention of low birth weight and child maltreatment from birth to two years in children whose mothers are identified as being high risks.*
- *Prevention of alcohol or drug use by children who have an alcohol or drug abusing parent.*
- *Prevention of mental health problems in physically ill patients.*
- *Prevention of conduct disorders in young children.*
- *Prevention of fetal alcohol syndrome in subsequent pregnancies."*

Patricia J. Mrazek, **Preventing Mental Health and Substance**